Late Stage Challenges in Huntington’s Disease Survey

Are you, a family member, or someone you care for at risk for Huntington’s disease? Or already diagnosed with HD?

If so, then we invite you to help us better understand the values and beliefs of members of the HD community regarding challenges in dealing with late stage HD.

Part of the survey will address end of life care choices. We are interested in learning about the values and beliefs that go into these choices for members of the HD community – especially in light of legislation recently passed in California called the “End of Life Option Act” that allows patients with a terminal illness to request a prescription for an aid-in-dying drug.

The survey is anonymous and will be completed online. It includes questions about your age and background, your family history, and your attitudes, beliefs, and concerns about current management of HD and end of life care choices in late stage HD.

The survey will take 10-15 minutes to complete and can be taken at: http://hdsa.org/hd-research/a-leader-in-global-hd-research/survey-on-end-of-life-issues-in-hd/

We thank you for your participation and time.

Sincerely,

Dr. Vicki Wheelock and Dr. Joshua Dayananthan
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